



# Closing the Gap: Training for and with People with Disabilities on the Interrelationship of Disability and HIV

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## Facilitator's Guide

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## **Short User Guide**

### **Who does this guide target?**

It is envisioned that this guide will be used to support facilitators who provide training on the interrelationship between disability and HIV, targeting people with disabilities. It needs to be used in combination with the participant's manual which includes basic knowledge on disability and HIV.

### **What you need to know before this workshop?**

Prior to this workshop you need to be familiar with general disability theories, issues around disability and development, the interrelationship of disability and HIV, disability legal obligations and the National Strategic Plan on HIV of the target country as well as good practices for health care and related services. You might need to update your knowledge of the websites provided at the end of this guide. You should also be familiar with basic facilitation techniques and adaptations for people with disabilities (see below).

### **How is the guide structured?**

This facilitator guide structures the course on a very basic level. The guide is written to support facilitators during the workshops. It is therefore written as concisely as possible and provides only instructions. In addition consult the participant's manual and provided websites. The workshop will cover the following areas:

- Issues regarding the definition of "disability"
- Vulnerability of people with disabilities to HIV
- Introduction to HIV-related disabilities
- National Strategic Frameworks and legal obligations
- Implications for HIV services
- Implications for rehabilitation services
- Disability inclusive health care services
- Action plan for each participant

### **How to work with people with disabilities?**

People with disabilities can learn anything if they are provided with the right format and learning tools. Therefore respect and encouragement to ask questions and disclose needs is crucial for the success of your workshop. The participant's manual for this course has been provided in word format (for the blind), as a full manual and as a simplified manual. You need to inquire prior to your workshop what type of assistance is needed and decide which manual is suitable for individual participants. Ensure that not only your workshop but also facilities such as the rest room are accessible.

During the workshop ensure that you verbalise and repeat discussions for people with visual impairments, use sign language as an alternative means of communication for people with impaired hearing and use the simplified manual for people with communication or learning disabilities. People with visual impairments can read the word version on their Braille readers. In the absence of such readers you will need additional assistance (an assistant or braille print out). Large print or the simplified manual (which includes enlarged print) can be used for people with mild visual impairments.

### **What techniques are referred to in this guide?**

This workshop uses, in particular:

- 1) **Power point presentations (PP):** These are 10-15min presentations with the provided PP slides followed by 10-15min of discussion and questions.
- 2) **Film screening:** The workshop works with the Film *Stepping into the Unknown*, a film that was developed for your workshops.
- 3) **Discussions:** These are facilitated with the whole group and focus on a particular question, theory or approach. Discussion can be introduced with a question, story, pictures or film material.
- 4) **Group work:** The participants work in smaller groups of 5-6 participants. You need to provide material, questions or a task for the participants. The allocated time should be around 30-60min and the participants work on one topic for the entire time. You can ask one representative from each group to present a short summary of the work.
- 5) **Gallery walk:** This is similar to group work (also 5-6 participants in each group). You need flip charts and pens. During the gallery walk the participants work on one problem for about 10-15min. Ideas are noted on a flip chart. After about 15min they change to the next flip chart. All the groups rotate and work on as many charts as your time allows.
- 6) **Brain storming exercises with mind maps:** This is a led discussion with the whole group. All participants work on one issue or question collecting their ideas. This course uses keycards to collect these ideas. Participants may be asked to write 3 or more related issues each on one card. Afterwards the participants and the facilitator discuss these ideas and place them on a wall or chart. This technique allows for clustering thereafter.
- 7) **Action plan development:** This is also a led discussion and usually facilitated at the end of a workshop or topic. The facilitator or a group representative facilitates this process. You should address the following issues Who, When and Where.

## Agenda Day One

8.30 - 9.00	Registration
9.00 - 9.30	Introduction
9.30 - 10.45	What is disability and HIV?
10.45 - 11.00	Tea
11.00 – 13.00	Disabilities and HIV
13.00 – 14.00	Lunch
14.00 – 16.00	Case studies: disability and legal obligations

## Agenda Day Two

9.00 – 9.30	Recapturing Day 1
9.30 – 10.00	National Strategic Framework and legal obligations
10.00 – 10.15	Tea
10.15 – 11.30	Accessing HIV services for people with disabilities
11.30 -12-30	Lunch
12.30 -14.30	Disability inclusive health care services
14.30 – 15.30	Ways forward
15.30 – 16.00	Evaluation and Closure

## Day 1

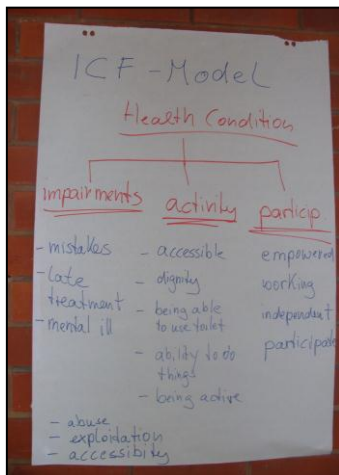
### Introduction: What is Disability?

You need: disability pictures, flip chart, board makers and power point app 2

- 1) **Warm up discussion:** Place pictures on tables across the room (see examples - appendix 1). Ask each participant to choose one of the laid out pictures and answer the question "What do you associate with disability?"
- 2) **Introduction/ discussion:** Ask participants to introduce themselves and their pictures explaining what the picture and disability means to them. You can also ask for their expectations of the workshop.



At the same time note the keywords of the participants on a chart (see picture below) clustering them in impairments, activities and participation. Don't use the ICF headings as yet.



3) **Summarise** the discussions using the participants' descriptions. Introduce the three disability categories: impairment, activity limitation and participation restriction (see example on the left) and go over to next part.

4) **Facilitator presentation:** Provide a short Power Point Presentation (PP) about different disability models. Use Power Point presentation in appendix 2.

## Disability and HIV: An Emerging Issue in ESA

*You need: Film Stepping into the Unknown (or Manguzi), cards, wall, PP disability and HIV, sticky tape*

- 1) **Film Screening:** Provide participants with 3 cards each. Ask them to note keywords related to the following question during the film screening: How are disability and HIV interrelated? Screen *Stepping into the Unknown*. Support blind participants with verbal descriptions of images. Afterwards remind participants to write three different issues/key words on the cards.



- 2) **Discussion:** Lead a short feedback discussion reflecting on first impressions.

- 3) **Brainstorm exercise:** Gather participants in front of a wall or chart and ask them to share the issues noted on their keycards. Participants explain their cards and place them on the wall. Make sure you repeat verbally for blind participants.

- 4) **Cluster:** The collected items on the wall provide you with an opportunity to cluster the issues and discuss with the participants.

- 5) **Facilitator Presentation:** Afterwards show participants the Power Point presentation on disability and HIV (use appendix 4).



## Interrelationship of Disability and HIV

*You need: Case studies in story form (see appendix) or cases from participants themselves, paper, pen*



- 1) **Group work:** Divide participants in groups of 5-6. Ask participants to describe the experiences of disability from one of the participants in their group (or use case studies in appendix) and use the worksheet from appendix 3. Prompt participants to use their case studies and

- a) Identify the different levels of disability using the ICF model

- b) Describe the interrelationship of disability and HIV.



- 2) **Participant Presentation:** Ask participants to present their cases and experiences to the combined group. Reflect on the different disability levels of the ICF.

## National Strategic Plans and Legal Obligations

*You need: Power point legal obligations and NSPs, CPRD extract, NSP extract, NSP framework*

- 1) **Discussion/Brain storming:** Ask participants to discuss and list which legal obligations, policies etc. guide their work on disability and/or HIV. Collect and write the names of these policies and legal documents on a flipchart. Make sure you repeat verbally for blind participants.
- 2) **Facilitator Presentation:** Show participants Power Point presentation from appendices 6 & 7. Discuss legislation and plans. Include international legislation and frameworks (see appendices 8 & 9) as well as national legislation and plans (collect latest versions before workshop!). Make sure you repeat verbally for blind participants.
- 3) **Gallery walk:** Use groups and case studies from previous exercise. Provide participants with your country's NSP extracts, CRPD articles (see examples in appendices 6 & 9). Ask participants to revisit their case studies and identify which legal obligations and national commitments have been violated. Rotate groups after 15 min, so participants can study another case and add their ideas.
- 4) **Summarise** and prepare group for next day



**End of day 1**

## Day 2

### Accessing HIV-Services for People with Disabilities

*You need: cards, sticky tape, pen, paper, flip chart, good practise examples*

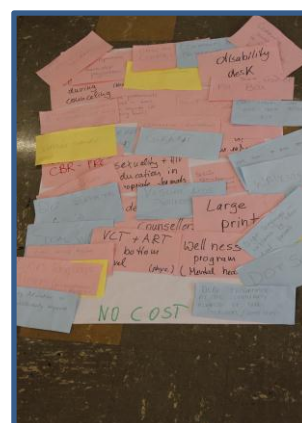
1. **Facilitator presentation:** Prepare a display of good practise material in the workshop facility. Repeat knowledge from previous day. Afterwards introduce participants to some of the good practise examples you brought to the workshop (see HEARD and Hesperian website for inspiration). Discuss selected examples and identify which material is useful for which disability group and service. Keep the materials exhibited for the exercises to follow.
2. **Group work:** Divide participants into groups of 5-6. Provide each group with 6-8 cards and ask them to identify needed services for the case studies that were discussed the previous day. Ask them to identify services for VCT, ART, rehabilitation (this includes physical functioning, activity levels and empowerment) and poverty alleviation.



3. **Brain storming and participant presentation:** Provide a two dimensional table using the impairment types (columns) and services (rows). Ask participants to allocate their cards/ideas to the right disability group and services.

4. **Clustering:** You now have the opportunity to discuss and cluster the displayed ideas with participants in:

- issues that can be addressed without any extra resources
- issues than can be addressed with the support of the facilitators
- issues that need more support from the health care department



5. **Close the session with a summary**

## Disability Inclusive Health Care Services

*You need: Checklist, pen, board makers*

1) **Introduction:** Introduce participants to the concept of accessible health care services as an example of disability inclusion. Introduce them to the Health Service Checklist (appendix 11) and its use for the evaluation of health services. The checklist also asks participants to identify 3 areas that they feel they can influence. This provides you with an opportunity to follow up with the long term impact of your workshop as well as to develop a customised action plan.

2) **Individual work** with worksheet (appendix 11): Participants complete individual checklist and evaluation form (example attached appendix 12).



3) **Individual presentations/discussion:** Ask participants to present and discuss their checklists and their ways forward. Inform participants that you will follow up with their action plans. Instruct the participants to note down their individual action plans and collect the health service checklists. This document will become part of your evaluation.

## Developing and Action Plan

*You need: flip chart, pen*

1) **Development of action plan:** Lead a discussion with the whole group on how they would like to take disability and HIV forward as a group. Identify next steps with the participants and collect them on the flipchart. Make sure the steps are feasible and achievable. Note when, by whom and what actions will be taken.

## Closure of Workshop

*You need: evaluation forms*

Ask participants to fill out the evaluation forms. Ask for some verbal feedback as well, collect the forms and close the workshop.

## **Useful links to update your resources**

HEARD resource center: [www.heard.org.za/african-leadership/disability](http://www.heard.org.za/african-leadership/disability)

Hesperian books and downloads: <http://hesperian.org/books-and-resources/>

UN Enable: <http://www.un.org/disabilities/default.asp?id=1560>

Source resources: <http://www.asksource.info>

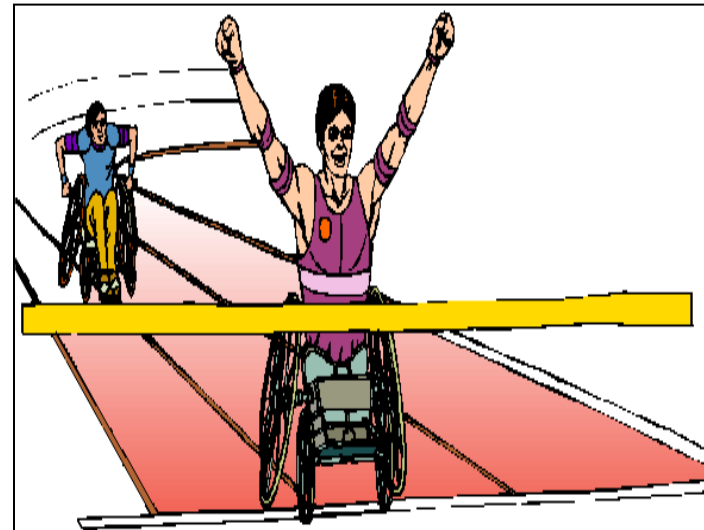
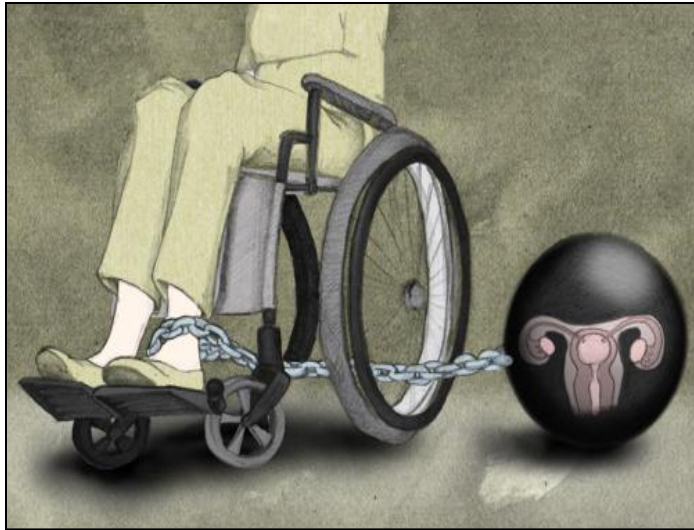
UNAIDS: [http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf)

CWGHR: <http://www.hivandrehab.ca/>

## **Appendices**

<b>Appendix 1</b>	<b>Disability pictures</b>
<b>Appendix 2</b>	<b>Power point presentation on disability models</b>
<b>Appendix 3</b>	<b>ICF case study model</b>
<b>Appendix 4</b>	<b>Power point presentation on disability and HIV</b>
<b>Appendix 5</b>	<b>Case studies in story form</b>
<b>Appendix 6</b>	<b>Power point presentation legal obligations</b>
<b>Appendix 7</b>	<b>Power point presentation NSP &amp; disability inclusive practice</b>
<b>Appendix 8a</b>	<b>Disability and rehabilitation: case studies 1&amp;2</b>
<b>Appendix 8b</b>	<b>Disability and rehabilitation: case studies 3&amp;4</b>
<b>Appendix 9</b>	<b>Extract of CRPD and UNAIDS recommendations</b>
<b>Appendix 10</b>	<b>Disability inclusive NSP framework</b>
<b>Appendix 11</b>	<b>Health service checklist</b>
<b>Appendix 12</b>	<b>Evaluation form examples</b>

Appendix 1 Examples of Disability Pictures







## HIV and disability overview

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“You are given a beautiful cocktail of tablets, and no one explains what they are for and how they would help me”

John Meletse  
Film "Stepping into the Unknown"  
[www.heard.org.za](http://www.heard.org.za)



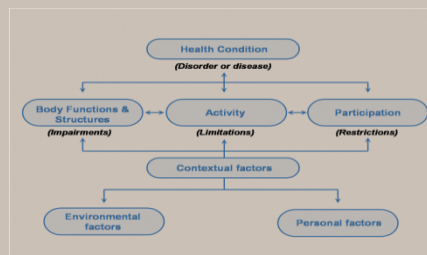
## What is disability?

- The **medical model** historically focuses on the dysfunction or impairment of the individual.
- The **social model** of disability asserts that the impairment itself is not an obstacle for the disabled individual, but is a socially-created problem and demands a political and social response.
- **Convention on the Rights of Persons with Disabilities (2008)**  
“... disability is an evolving concept and results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others ...

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”



## The ICF as a Model of Disability



## The ICF as a Model in the Ara of HIV and ART

HIV as a health condition

**Impairments** e.g. blindness caused through TB treatment

**Activity limitation** e.g. not able to see and read

**Participation restriction** e.g. exclusion from work, stigma

**Environment** no life skill or workplace adjustment....

**Personal Factors** depression, gender, hope ...



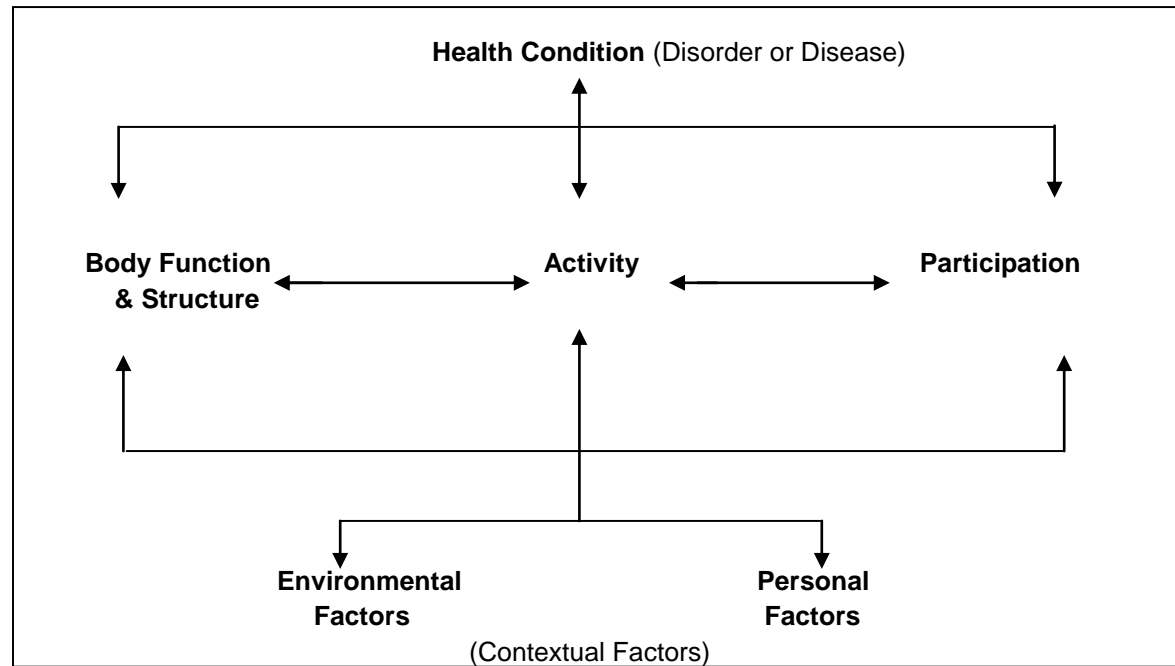
# THANK YOU

For more information on HEARDS work: [www.heard.org.za](http://www.heard.org.za)

For more information visit the HEARD disability and HIV resource centre  
[www.heard.org.za/african-leadership/disability](http://www.heard.org.za/african-leadership/disability)



Where do you locate your disability?









### HIV and disability overview

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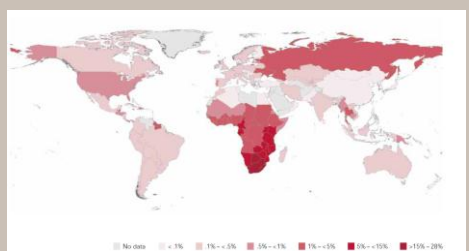
HEARD  
Health Economics and HIV/AIDS Research Division  
University of KwaZulu-Natal

“You are given a beautiful cocktail of tablets, and no one explains what they are for and how they would help me”

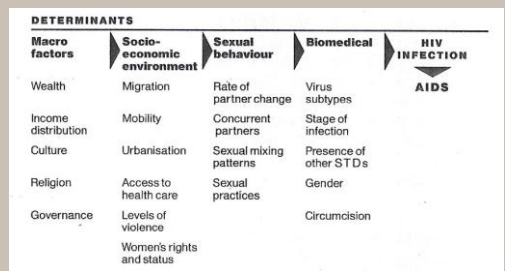
John Meletse  
Film "Stepping into the Unknown"  
[www.heard.org.za](http://www.heard.org.za)



### Global View of the HIV Epidemic 2009

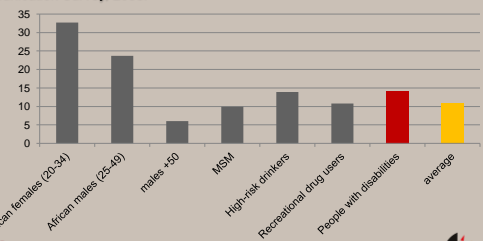


### HIV-Determinants



### HIV-Prevalence of at Risk Populations in South Africa

Source: South African National HIV Prevalence, Incidence, Behaviour and Communication Survey, 2008:





### Interrelationship of disability /mental health and HIV

People with disabilities	PLHIV who develop disabilities	People who care for PLHIV especially young carers
<ul style="list-style-type: none"> <li>increased risky behaviour</li> <li>increased risk of sexual abuse and less access to justice</li> <li>negative attitudes from health care staff</li> <li>access problems</li> <li>influences adherence</li> </ul>	<ul style="list-style-type: none"> <li>mental health disorders e.g. depression, schizophrenia, anxiety, substance abuse</li> <li>impairments such as e.g. reduced neuro-cognitive impairments, blindness, deafness, skin problems, digestive problems ...</li> <li>episodic disabilities</li> </ul>	<ul style="list-style-type: none"> <li>AIDS related activity limitation is associated with increased child healthcare task, less school attendance, food insecurity and educational outcomes</li> </ul>



## Currently discussed approaches

<p style="text-align: center; border: 1px solid #ccc; padding: 5px;">People with disabilities</p> <p><b>Access to health services and education</b></p> <ul style="list-style-type: none"> <li>• human rights approach</li> <li>• disability specific sex education</li> <li>• simplified HIV information</li> <li>• psychological support for people with intellectual disabilities in rape cases</li> <li>• integration of mental health issues in training of health care staff</li> </ul>	<p style="text-align: center; border: 1px solid #ccc; padding: 5px;">PLHIV who develop HIV-related disabilities</p> <p><b>Use and adopt screening tools:</b></p> <ul style="list-style-type: none"> <li>• mental health (SF12, HTQ, CES D, RIME – MD, ADLs)</li> <li>• mental health interventions</li> </ul> <p><b>Rehabilitation</b></p> <ul style="list-style-type: none"> <li>• clinics and hospitals</li> <li>• HBC and CBR</li> <li>• adaptation in the workplace</li> </ul>	<p style="text-align: center; border: 1px solid #ccc; padding: 5px;">People who care for PLHIV especially young carers</p> <p><b>Support and care</b></p> <ul style="list-style-type: none"> <li>• apply CRPD concepts of universal access and reasonable accommodation for people with disabilities</li> <li>• Work placement adjustments for PLHIV</li> <li>• care support grants</li> </ul>
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# THANK YOU

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For more information visit the HEARD disability and HIV resource centre [www.heard.org.za/african-leadership/disability](http://www.heard.org.za/african-leadership/disability)




## Appendix 5 Case Studies in Story Form

### Case 1

**Susan Mshoka** was born 1973 in Zambia. In 1982, as a 9 year old, she lost her hearing to meningitis. With the support of her parents she graduated from school. She married, but her first husband died early. A few years later she remarried her second husband who was also deaf. Around the year 2000 or 2001 Susan began to experience HIV-related illnesses such as severe diarrhoea, headaches, lymph node enlargements, vaginal discharge, hair loss, loss of appetite and weight loss. She did not understand what had caused these problems.

As so many people in the deaf community, who have little access to HIV information, she hadn't acquired information about HIV and AIDS. Often programmes excluded people with disabilities as it is believed that they are not at risk of HIV infection. Susan was unable to gain back her health and in 2002 she was advised to go for an HIV test. First she refused as she was too scared, just the thought of the test made her shiver.

Once she had the courage to go for the test she was faced with another dilemma, there was no sign interpreter at the counseling centre. She had to provide and pay for her own interpreter. Susan lost all hope of living after her HIV-positive diagnosis and was diagnosed with depression shortly after. Her husband refused to test. He accused her of infecting him with the virus; however Susan recalls that he was the one who slept out frequently. In 2006 her husband died of AIDS, leaving her behind to look after the children. In the same year she received ARV treatment and her health was slowly restored. However many of her deaf peers, not realising the impact of HIV on their lives, died.

Through the inspiration of another disability activist who also lives openly with HIV in the US , she gained confidence to speak out on HIV and disability issues. She became the first Zambian women with disability who disclosed her status publically and also provided her testimony to the Zambian president David Kenneth Kaunda at his office. She has formed a support group in her home district of Petauke. However despite her successes and courage, Susan remains a single mother who, based on her disability and HIV status, finds it difficult to make ends meet and provide for herself and her children. She still has no sign interpreter at her local clinic and hospital.

## Case 2

Ronald Ndlovu was born in 1966 and raised in a typical Zimbabwean family as the third child out of six siblings. After graduating as a school teacher from Mkoba Teacher's College in Gweru in 1992, he was employed in the Tsholotsho district in a rural school known as Zimwatuga Primary school. He got married to his first wife and shortly after they had their first child. In 1998 his wife became ill with TB.

However HIV had not yet been diagnosed. Two years later their second child was born, it was found to be HIV positive. By that time Ronald's health had also deteriorated. He was coughing, his glands were swollen and he developed blisters. He went from one treatment to another without getting any better but was too scared to go for an HIV test. In 2004 he finally went to find out about his status. At the same time he fell ill again and was admitted to hospital several times and later put on ARV treatment. While the medication was able to save his life, it was not able to save his sight.

Ronald was declared visually impaired at his discharge from the hospital and sent back home to deal with his blindness by himself without any kind of rehabilitation or support. His first wife left him, leaving the children behind with him. He had to resign as a teacher on medical grounds. Ronald's life as he knew it was over and he entered the "vicious cycle of poverty and disability", barely able to make ends meet and with many worries in regards to himself and his children's future.

However Ronald's personal strength and the support from a disability support group in Bulawayo gave Ronald new life. He eventually found a book writer who taught him Braille. Through his personal perseverance he learnt how to adapt to a life without sight. He became an advocate on HIV and disability and helps many people in similar situations. In 2010 with the support of a local NGO he reapplied for his teaching position with the department of education. He is now integrating blind children into a mainstream primary school in Zimbabwe.

### Case 3

South Africans are shocked and outraged over a disturbing video of seven teenage boys and young men sexually assaulting a mentally-handicapped teenage girl that has gone viral.

The video, recorded on a cell phone, shows the men gang raping the 17-year-old girl who went missing March 21 and offering her 25 cents to keep quiet.

“The girl can be heard pleading with the boys to stop. They crudely jest and crassly spur one another on,” journalist Mandy Weiner reported.

The accused range in age from 14 to 20 years old and are suspected of holding the girl as a sex slave in a Soweto township. Police found the girl on Wednesday in the home of a 37-year-old man who has also been arrested.

CNN reports that the Daily Sun, a local tabloid, alerted the police after a concerned mother whose daughter was watching the video handed it over to the paper on Tuesday. The mother confiscated her daughter’s phone and a work colleague said they recognized some of the boys and advised her to take the video to the newspaper.

According to Reuters, a front page editorial of the Star newspaper, one of South Africa’s biggest-circulation dailies, labeled the incident “Our Disgrace,” and government spokesman Jimmy Manyi described it as a “barbaric act.”

For as much discussion as the rape has raised, it’s unfortunately not all that uncommon of a crime in the country. Non-Governmental Organizations estimate a woman is raped every 26 seconds in the country. Other estimates say an average of 181 people are raped or sexually assaulted per day.

The men appeared in court yesterday and prosecutors said they could seek life in prison for the crime. They are being held until their next court date next week as the rest of the country continues to react.

“This episode must force us to take a serious look at ourselves and ask: how did we get here?” the Star editorial read. “How did we, as a people, raise monsters who find a joke in this repugnant act.”

See more under: <http://madamenoire.com/167499/outrage-7-men-face-charges-for-gang-raping-mentally-disabled-girl-in-south-africa-on-camera/>

## Case 4 (from SANAC report 2009)

### John's story

John Meletse was born deaf and diagnosed with HIV in 2002. As a gay man John faced discrimination in society. His mother was shocked when he disclosed his HIV status. She reacted with shock and disbelief. She could not believe that John could be affected by HIV as he was deaf and outside of influence of the society. The only support that was available to John was from his grandmother, who accepted and loved him, regardless of his status.

When John went for Voluntary Testing and Counseling, he was met with the same inhumane treatment at the clinic as he has been exposed to over the years. The reaction from the nurses at the clinic was a combination of shock, guilt and pity. Interestingly, there was a poster on Sign Language on the wall in the clinic but none of the nurses were familiar with Sign Language. After being passed from one nurse to



## John Meletse

**"You are given a beautiful cocktail of tablets, and no one explains what they are for and how they would help me". John Meletse, Deaf, Gay and HIV Positive.**

another several times, one nurse took his blood sample without pre-counseling. The results were given to him on a piece of paper written HIV positive and he was dismissed without post-test counseling. The cold experience at the clinic continued when John went to seek treatment.

This was the pattern for John until such time as he went to the clinic with a Sign Language Interpreter, called Ruth. This improved John's understanding of his condition and the treatment he was receiving. Working with Ruth improved John's relationship with the health professionals at the clinic and even on occasions when John visited the clinic alone, he was able to interact with the health personnel better.



### **Case Study 5: Code name Sandile**

Sandile was born on the 5th of June 1972 in a semi-rural area of KwaZulu-Natal. She only managed to finish Grade 3 where she acquired basic reading and some English language skills. Sandile married and had children; however she is now separated from the father of her children. She does not work and lives on a child support grant.

It is not known when Sandile became infected with the virus, however she suspects that it was no later than 2000. During the period between 2000 and 2008 she recalls being affected by shingles, discharge and rashes, loss of weight and appetite.

In 2008 her husband tells her that he “*is sick*” (meaning HIV positive). Sandile goes for an HIV

test and is diagnosed positive. Rashes on her vaginal track come and go and when they are there they are increasingly painful. She knows this is “*one of the symptoms of HIV*” and to get relief she goes to the hospital to collect medicine for her sores. In 2010 Sandile gets shingles and goes to the hospital again. She is finally put on ARV treatment. During an episode of TB she receives a series of injections. Around this time she starts experiencing problems with her eyesight.

*Sandile: My eyes just felt as if they had dust, they had dust just like dusty sand. It got blurry and I could not see. It started slowly at first. I usually looked at Timothy’s house across from here to check if I could still see. It went on and on until eventually I could no longer see the house. I can’t see the house at all now.*

By now Sandile is more or less blind with some little vision left when she is indoors. She still battles with her appetite and has not put on weight. She worries about this and “feels bad because she knows that she should eat”. She struggles with the adjustments to a life with blindness and says that she “cannot walk on her own” and has problems with her house activities. *She says: “I can just see a little bit. I cannot go from here to the kitchen to cook. I will never be able to do washing and the cramp catches me too and I fall down”.*

The doctors have prescribed a different type of TB drug and Sandile thinks that this will improve her vision. However her condition persists – she cannot see anything when she is outside but has some fraction of vision left indoors. She also experiences problems with her legs and feet which are cramping. The loss of eyesight and cramps affect her ability to access treatment.

*Sandile: “Yes the feet it started at that time because I could go on my own to the clinic for my injection but when I got the foot problem then my eyes started too. I was then no longer able to walk on my own to the clinic”.*

She also experiences problems with sensations of her body and sometimes loses feelings for her bodily functions such as having to relieve herself on the toilet.

*Sandile: It is still there when I hold here but now I can feel that I want to get to the toilet which I could not before. I couldn’t even feel that I needed to get to the toilet.*

She has reported the cramps and urination problems at the clinic visits but has not received any help or medication. She worries about her condition particularly as she is afraid of a stroke.



Sandile explained how she used to enjoy “doing the garden”, planting, sewing with another lady and keeping her house clean and tidy. She also used to sell sweets and biscuits and used the money from this income to buy necessities such as electricity cards and to have pocket money for herself and the children. She now no longer has the strength and capacity to do this and explains

*Sandile: I no longer have the strength to go to the garden. ... I am unable to thread the needle of the machine. I said I was no longer able to manage and even the welfare people I told them I wasn't right. ... I am no longer doing anything. But if they put water for me I am able to wash myself. They give me something to dress and I can dress myself. There is nothing else I can do. .... I walk and you see if I walk with somebody they tell me if there is a bad spot but if I walk on my own I fall down everywhere. .... I was not negatively affected it is only when I was no longer able to see and walk. That is when I was affected most. I got stressed and lost weight. I could see it was affecting me and secondly I was affected by the cramp which prevented me from walking. I could no longer see my children. That affects me. I can no longer watch TV. If I am sitting here in the room I only listen to Generations and the news. That is all I can listen but I cannot see what is happening. I cannot dial on the phone.*

One of her main worries is the children who she feels she can no longer support. She also feels that the children sometimes take advantage of her blindness.

*Sandile: I am unable because I can't even see them. They see me and I don't see them. .... I noticed when I lost my sight. I then realised that I had a problem. Even when they (the children) return from school I just hear by their voices. I can't see them. I don't know what they wore to school or how they are, I just can't see them. .... Yes they do listen to me but there are times when they don't follow my instructions as I expect them to, because they know that I can't see.*

She explained that she is highly dependent on other people e.g. if she needs to go to the hospital somebody needs to come with her, she cannot afford to go with a private car or taxi. She also explained that when she eats food she cannot even see what she is eating – she does not refer to anybody to explain or help her with this task. Sometimes her situation overwhelms her and she “feels bad ... and thinks of many things ” (depression?). The company of other people seems to be very important to her as she “does not like to sit in one place”.

*Sandile: I feel very bad about it. I am stressed if I stay alone because if I am sitting by myself and thinking I think of many things. It is better if I am in the company of people because at least I forget my problems for a while but if I am by myself it comes forcefully. .... Yes they do; the neighbours they come but I am somebody who likes to move around and keep busy. I do not like to sit in one place. I used to do everything for myself. I didn't even depend on sending people not even sending the children to do things for me. I liked to do things myself all the time.*

Her main support at home is the children, who she sends to do things for her. She “is frustrated as she feels that “... she is a thing that cannot do anything”.

## Case study 6 Code name: Mfana

Mfana was born on the 31. March 1982 in a semirural area of KwaZulu-Natal, South Africa. He battled at school, and just finished grade 8 and tried to enrolled in a Technical college. He did not finish his training their either.

In 2008 Mfana discovered that he is living with HIV. He started to develop a number of opportunistic infections such as TB and sores simultaneously. Before the onset of ART, Mfana experiences a number of changes in his body. For instance he refers to changes in his skin and hair. The hair started to “*become too fine*”, like “*Indian hair*” and the skin became “*itchy*” and peeling. A little later he got sores all over his body “*it was like a belt here*” (maybe Shingles?). The sores were itching, leaking water and very painful. He first experienced it when he was diagnosed with TB. The conditions improve while being on TB treatment but came back later. At the same time he also experienced challenges with eating as he battled to digest food and often “*spit it out*”. Additionally he experiences challenges with his sight and eventually he becomes blind during this period leaving him with one eye that can see partially. He almost dies of diarroa in 2009 and attributes this to some treatment he got. Shortly thereafter he starts ARV treatment. With treatment a number of his symptoms’ related to digestion, skin and hair problems disappear.

However he also refers to a number of experiences post ARV onset period such as pain in his entire body and pain in his eyes which turn into headaches. Sometimes he feels “*dizzy*” and his “*head is spinning*”. He also experiences loss of memory and concentration. He describes these experiences as being “*better now but that it comes and goes*”.

He explains that people recognized the change of his skin and hair as signs of AIDS and that he was very worried about people gossiping. When the treatment helped to repair his skin and hair he felt much relief as he had to worry less about stigma. However, his visual impairment has led to him to believe that he relies on other people for his personal hygiene, house work etc. He believes that he cannot wash himself, make his bed or fold his clothes.

Mfana: *Oh you mean maybe to do things for me, yes food washing for me I am forced to ask them for help. I cant turn so they hold me at the neck and these places and I do this because I won't lie I cannot hang up the clothes. Making the bed also beats me sometimes, folding the clothes too.*

He also finds basic activities such as walking upstairs, making food and pouring something to drink challenging and says that he needs others to help. Despite this negative self image he says that he tries to perform tasks in the house. His tetimony does not account for any type of rehabilitation.

Mfana explains that acceptance of his illness, change in behavior “*do things carefully*”, the support from his family and the financial support from the disability grant helps him to cope.

Mfana: *You see I have now accepted my illness. If somebody says or does something I do no take it to heart. I stand aside and I don't even think about it.*

Mfana: *I can say it is me and the money I get that enables me to get these glasses. At least it improves the eye that can see ... What helps me is the money*

However social activities he is no longer participating in. For instance he explains that he is no longer *"talking to the other boys .... things like us talking. Talking like and enlightening each other on things"* or drinking with them.

Fortunately the mother of his children is working. However he has not disclosed his condition to some of the children (including the blindness) as *"the child hasn't noticed what I am"* yet. He wishes to be able to go back to work and support his children. However at the stage of the interview his financial affairs were regulated by his family. He gets a disability grant which his father collects for him. Despite this grant he has no bank account and says that he doesn't need one as *"he has no money"*.



## Legal Obligation on Disability Brought into the Context of HIV and AIDS in ESA

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“We have to accept persons with disabilities or persons with HIV and AIDS in the community as human beings as people who can do a lot of things ... ”

Issac Nkangatsang  
Film "Stepping into the Unknown"  
[www.heard.org.za](http://www.heard.org.za)






## Disability rights in Africa (building blocks)

The Convention on the Rights of People with Disabilities (CRPD, 2006)

The Maputo Protocol on Human and People's Rights and on the Women in Africa (1995)

The African Charter on the Rights and Welfare of the Child (1989)

The African Charter on Human and People's Rights (1981)



## Disability, Rights and Hiv in South Africa

South African NSP and Disability Sector Plan (2007 – 2011)

South African disability and HIV legislation: e.g. White Paper on Integrated Disability Strategy (1997)

South African general legislation: e.g. Employment Equity Act, Promotion of Equality and Prevention of Unfair Discrimination Act (2000)

South African Constitution (1997)

## Rights associated to the CRPD

- Education
- Health & Rehabilitation
- Work and employment
- Assistant devices
- Access to public buildings and events
- Access to justice with accommodation of your needs
- Independence, dignity and equality




## Uptake of international commitments

Country	African Charter	Maputo Protocol	African Children's Charter
Angola	Yes	No	Yes
Botswana	Yes	No	Yes
Burundi	Yes	No	Yes
DRC	Yes	No	No
Kenya	Yes	No	Yes
Lesotho	Yes	Yes	Yes
Madagascar	Yes	No	No
Malawi	Yes	Yes	Yes
Mauritius	Yes	No	Yes
Mozambique	Yes	Yes	Yes
Namibia	Yes	Yes	No
Rwanda	Yes	Yes	No
Seychelles	Yes	Yes	Yes
South Africa	Yes	Yes	Yes
Swaziland	Yes	No	No
Tanzania	Yes	Yes	No
Uganda	Yes	No	Yes
Zambia	Yes	Yes	No
Zimbabwe	Yes	No	No



Legend:  
■ Signed and ratified convention and protocol  
■ Ratified Convention  
■ Signed convention and protocol  
■ Signed convention  
■ Not signed

Ratification of CRPD 2010




## Implementation of international commitments

Dualist	Monist
<p>Treaties and covenants do not form part of the domestic law until national legislation has been enacted incorporating the provisions into domestic law.</p> <ul style="list-style-type: none"> <li>• Angola</li> <li>• Botswana</li> <li>• Kenya</li> <li>• Lesotho</li> <li>• Malawi</li> <li>• South Africa</li> <li>• Swaziland</li> <li>• Tanzania</li> <li>• Uganda</li> <li>• Zambia</li> <li>• Zimbabwe</li> </ul>	<p>Treaties and conventions become directly applicable once ratified and no additional national legislation is required.</p> <ul style="list-style-type: none"> <li>• Namibia</li> <li>• Madagascar</li> <li>• Mozambique</li> <li>• Rwanda</li> </ul>



## Domestication of disability rights

### Examples of Good Practice in the region

- The right to equality and non-discrimination
- The right to care, including health care
- The right to employment
- The right to participation
- Legal protections and penalties
- Interlinkages of disability and HIV in policies



## Gaps and weaknesses in domestication

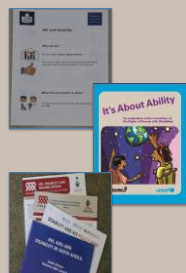
- Separate development of disability and HIV legislations – no systematic approach to address the links between HIV and AIDS
- Limited obligations to ensure the availability and accessibility of specialized goods, services and facilities, including the provision for access to information
- Limited provision for access to justice
- Limited provision for data collection on disability as well as disability and HIV
- Limited recognition of the gender dimension of disability
- Limited inclusion of disability into National Strategic Plans on HIV



## Two Simple Principals



## Examples within Legal Services in the Context of HIV



Human Rights Watch

UNICEF CRPD translation for PWDs

SAVE Program for Survivors of sexual violence



# THANK YOU

For more information visit the HEARD disability and HIV resource centre  
[www.heard.org.za/african-leadership/disability](http://www.heard.org.za/african-leadership/disability)

Or the Good Practise Collection at:  
[www.heard.org.za/african-leadership/disability/resources](http://www.heard.org.za/african-leadership/disability/resources)





## National Strategic Plan on HIV and AIDS and Integration of Disability Mental

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“We have to accept persons with disabilities or persons with HIV and AIDS in the community as human beings as people who can do a lot of things ...”

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## What is an NSP?

National HIV and AIDS Strategic Plans (NSPs) set out a country’s response to HIV and AIDS, providing for the needs of those infected, affected and vulnerable to HIV and AIDS. As a result, NSPs are a critical determinant in the allocation of national resources towards HIV and AIDS. In many instances the funding, resources and human capacity that will be devoted to the national HIV and AIDS responses will be utilised within the context of the strategies described in the NSP. Where an NSP is silent on an issue, issues of disability will not receive national attention. The structure of an NSP may be as follows:

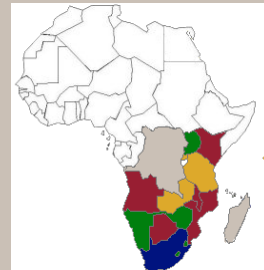
1. Situation Analysis
2. Structure and General Approach
3. Guiding Principals
4. Priority Areas / Strategic Objectives (4.1 Prevention, 4.2 Treatment, Care and Support, 4.3. Monitoring and Evaluation, 4.4. Human Rights)
5. New: Operational Plan



## Disability in the NSPs of Southern and Eastern Africa

Table 2: Emerging responses within NSPs in Eastern and Southern Africa

- NSP fails to recognise disability as an issue in any way
- NSPs do not specifically identify disability as an issue but nevertheless include some reference to disability within the Response
- NSP identifies disability as an issue but fails to operationalise this concern
- NSP identifies disability as an issue and takes selective steps to operationalise this concern
- NSP identifies disability as an issue and takes extensive steps to operationalise the issue



## Disability Issues in the new South African NSP 2012-2016

- 1) Situation Analysis
- 2) Background Information to Strategic Objectives
- 3) Covers Vulnerability of PWDs
- 4) Covers HIV related disability
- 5) Covers Monitoring and Evaluation



## Disability Inclusion in South Africa's new NSP Strategic Objectives

The NSP has identified a number of strategic objectives that will help South Africa reach these goals. These are:

- 1 Address social and structural factors that drive these epidemics, influence their impact, and affect the way we care for affected people.
- 2 Prevent new HIV, STIs and TB infections through a combination of interventions.
- 3 Sustain health and wellness, primarily by reducing deaths and disability from HIV, AIDS and TB.
- 4 Protect the human rights of people living with HIV and improve their access to justice.



## Disability Issues in the New Rwandan NSP

- 1) Situation Analysis, The impact of HIV in Rwanda p.2 + Other Factors Contributing to the Spread of HIV p 31
- 2) Organisation of Rwanda's Response to HIV and AIDS p 32
- 3) Equity and Human Rights p 44
- 4) Intermediate Outcome 1.1.1 Reduction of Risk Sexual Intercourse p. 52
- 5) Other vulnerable and most at risk populations p 58 - key strategies
- 6) Institutional Framework p. 89 and Civil Society Organisations p. 90
- 7) Component 11: HIV Evaluation and Research p. 118



## Two Simple Principals



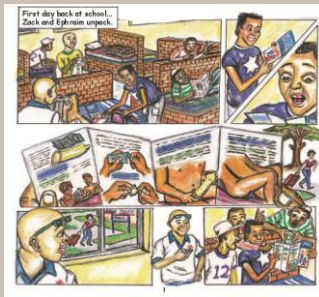
Universal design



Reasonable accommodation



## HIV Information for deaf Youth



## "Sexuality Education for young people with disabilities"



Rebecca Johns 2007



## Sign Language for Health Service Providers



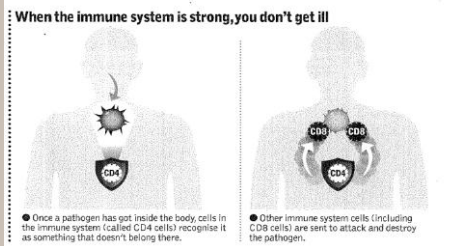
## HIV Test for People with Intellectual Disability



## Medication Packaging for the Visually Impaired



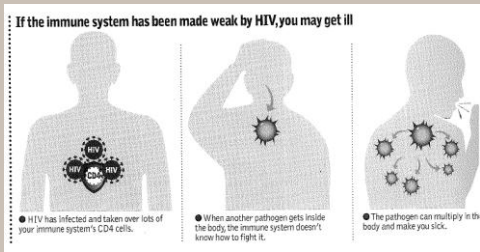
## Simplified HIV Information



NAM 2009



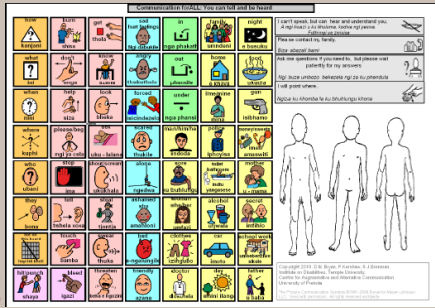
## Simplified HIV information



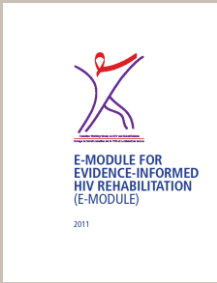
NAM 2009



## Identifying Sexual Abuse



## Rehabilitation for PLHIV



## THANK YOU

For more information visit the HEARD disability and HIV resource centre [www.heard.org.za/african-leadership/disability](http://www.heard.org.za/african-leadership/disability)

Or the Good Practise Collection at: [www.heard.org.za/african-leadership/disability/resources](http://www.heard.org.za/african-leadership/disability/resources)





## Case Study 1

<b>Info</b>	<b>Context</b>
<b>Gender</b>	Woman
<b>Age</b>	42
<b>Date of HIV diagnosis</b>	1999
<b>Treatment</b>	ARVs
<b>Living situation</b>	She lives with her elderly mother and 3 children in a shack in an informal settlement. The father of the children works in the mines in Johannesburg, and sends money when he is able.
<b>Income situation</b>	She earns an irregular income from selling airtime at a stall near her home. The household is also supported through the old age pension of her mother.
<b>Impairment</b>	She experiences frequent episodes of high fevers, chills, tiredness and headaches (CMV)
<b>Activity limitation</b>	She has low endurance for any physical activity e.g. walking, washing clothes, cleaning the house
<b>Participation restriction</b>	She has a limited role in earning a living for the household as she is unable to walk long distances or sit at the stall for long periods

## Case Study 2

<b>Info</b>	<b>Context</b>
<b>Gender</b>	Man
<b>Age</b>	47
<b>Date of HIV diagnosis</b>	1997
<b>Treatment</b>	ARVs
<b>Living situation</b>	He lives with his common law wife and two children in a township. However, he is frequently away from home due to the nature of his work.
<b>Income situation</b>	He has been working as a truck driver, doing long haulage trips between the major cities. However, there have been many recent retrenchments in the company and his job security is threatened.
<b>Impairment</b>	He experiences periods of concentration and memory loss, which occur more frequently when he is tired or under stress.
<b>Activity limitation</b>	He is not able to concentrate fully on driving over long distances and finds the many locations that he travels to confusing. Several times he has been unable to remember directions.
<b>Participation restriction</b>	Increasingly he is being seen as unreliable and even a danger on the roads. As a result his job and income are being threatened.

## Appendix 8 Case Studies

### Case Study 3

Info	Context
Gender	male
Age	24
Date of HIV diagnosis	February 2004
Treatment	January 2009
Living situation	He lives with his brother and his family in a government housing township (2 bedroom house)
Income situation	<ul style="list-style-type: none"><li>• He used to work as an assistant in a local business (filing and typing) to finance his studies</li><li>• He lives from his brothers income but wants to apply for a disability grant</li></ul>
Impairment	<ul style="list-style-type: none"><li>• His CD4 count is well established at 600</li><li>• Half of his body is paralysed as a result of a stroke in 2010</li><li>• He experiences fatigue</li></ul>
Activity limitation	<ul style="list-style-type: none"><li>• He limps while walking (only possible with walking stick)</li><li>• He cannot use his right hand and arm</li><li>• He has problems with daily task such as dressing, eating, waiting at the taxi rank (standing)....</li></ul>
Participation restriction	<ul style="list-style-type: none"><li>• He had to interrupt his studies as he has difficulties with paying for his fees (as he cannot work as before), taking notes during the lessons, getting transport and accessing buildings</li><li>• His girlfriend (who was also HIV positive) left him after the stroke</li><li>• His brother's wife is concerned that he will drain their resources and wants him to move back to the parents house in a rural area</li><li>• Public transport is not suitable for him as he cannot stand and wait for long times</li><li>• Some people call him names because of his disabilities</li><li>• He has his own cutlery at home because his brother and the wife are afraid of getting infected with HIV</li></ul>

## Case Study 4

Info	Context
Gender	women
Age	23
Date of HIV diagnosis	July 2008
Treatment	December 2008
Living situation	Lives with aunt and uncle in township, two bedroom house, simple furniture
Income situation	<ul style="list-style-type: none"><li>• She used to do temporary work as a waitress however she is unemployed since she experiences problems with her feelings in her hands and feeds</li><li>• Her aunt is working as a domestic worker and her uncle as a labourer</li></ul>
Impairment	<ul style="list-style-type: none"><li>• Her CD4 at 800 (stable and healthy from a medical perspective)</li><li>• She experiences numbness, tingling and pain in the feet and hands</li></ul>
Activity limitation	<ul style="list-style-type: none"><li>• She experiences nuisance during walking, some days she cannot walk at all because of the pain,</li><li>• As a result she has problems with house work, difficulties with using a computer (typing) ...</li><li>• Even daily task such as eating are difficult / the cutlery is just to slippery for her</li></ul>
Participation restriction	<ul style="list-style-type: none"><li>• She cannot support house work as expected from young women.</li><li>• People perceive her as lazy and clumsy.</li><li>• Some friends and neighbours don't want to be with her anymore as they suspect she is HIV positive</li></ul>

## ***UN (2008) Convention on the Rights of Persons with Disabilities***

### **Key provisions in the context of disability, HIV and AIDS include the following:**

Article 5 protects the rights of all persons to equality, prohibits discrimination on the basis of disability and guarantees to persons with disabilities equal and effective legal protection against discrimination on all grounds

Article 8 provides for States to take measures to raise awareness regarding and foster respect for the rights of disabled people, and to combat stereotypes, prejudices and harmful practices relating to persons with disabilities

Article 9 promotes accessibility for disabled people, and requires States Parties to take measures to ensure access to the physical environment, transportation, information and communications and to facilities and services.

Article 12 provides disabled people with equal rights to recognition as persons with legal capacity before the law

Article 13 requires States Parties to ensure effective access to justice for disabled people

Article 15 protects disabled people from cruel, inhuman or degrading treatment or punishment, including being subjected without his or her free consent to medical or scientific experimentation

Article 16 requires States Parties to take measures to protect disabled people from exploitation, violence and abuse

Article 17 protects the rights of disabled people to physical and mental integrity

Article 22 protects disabled people from unlawful invasions of their right to privacy, including the privacy of personal, health and rehabilitation information

Article 24 requires States Parties to recognise the rights of disabled people to education

Article 25 provides persons with disabilities with the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability

Article 26 provides for State Parties to take appropriate measures to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life

Article 27 recognises the rights of disabled people to work on an equal basis with others

Article 28 requires States Parties to recognise the rights of disabled people to an adequate standard of living for themselves and their families

Article 29 provides that States Parties guarantee disabled people political rights to ensure that disabled people can participate in political and public life, and

Article 30 requires States Parties to collect appropriate information, including statistical and research data to enable them to formulate and implement policies to give effect to the UN Convention.

## ***UNAIDS (2006) International Guidelines on HIV and Human Rights***

### **Key recommendations in the context of disability, HIV and AIDS include the following:**

Guideline 1 recommends that States establish a co-ordinated, participatory, transparent and accountable national framework in their response to HIV integrating HIV policy and programme responsibilities across all branches of government

Guideline 2 recommends that States support community organisations to become involved in all phases of HIV and AIDS policy design, programme implementation and evaluation

Guideline 3 recommends that States review and reform public health law and policy to ensure that it addresses HIV, and protects rights in the context of HIV and AIDS

Guideline 5 says that States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups such as people living with HIV and people with disabilities from discrimination

Guideline 6 says that States should take measures to ensure the availability and accessibility of quality goods, services and information for HIV prevention, treatment, care and support

Guideline 7 recommends that States implement and fund legal support services that will educate people about their rights, provide free legal services to enforce these rights, develop expertise on HIV-related issues and utilise the courts and other means to protect the rights of individuals

Guideline 8 recommends that States should promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities

Guideline 9 says that States should promote creative education, training and media programmes explicitly designed to change discriminatory attitudes and stigmatisation associated with HIV and AIDS to one of understanding and acceptance

Guideline 10 recommends that the States encourage the development of private sector codes of conduct translating human rights standards into professional responsibilities and practice, and

Guideline 11 says that States should ensure monitoring and enforcement mechanisms to guarantee HIV-related human rights, including those of PLHIV, their families and communities.



# Framework for the Inclusion of Disability in the National Strategic Plans on HIV and AIDS

# Framework for the Inclusion of Disability in the National Strategic Plans on HIV and AIDS

## Context and Approach

The World Health Organisation (WHO) estimates that 15% of the world's population, [2, 3] have a disability, making People With Disabilities (PWD) the world's largest minority [4]. It is estimated that the number of PWDs is increasing "due to population growth, ageing, emergence of chronic diseases and medical advances that preserve and prolong life"[4]. Eighty percent of PWDs live in resource poor settings, where they have difficulties in accessing the most basic services to accommodate their needs [2, 4]. With the signing of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) [1], many countries have now committed to providing services that are accessible to and inclusive of people with disabilities, including services for the prevention, treatment, care and support of HIV and AIDS.

*Disability is more than a medical phenomenon, it is also socially constructed. The CRPD (2008) defines disability as a "result from the intersection between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis"[1].*

The growing available evidence suggests a strong interrelationship between HIV, AIDS and disability. First, people with physical, intellectual, mental or sensory disabilities are as likely, if not more likely, to be at risk of HIV infection. They have 1) insufficient access to HIV prevention information, (2) are sexually active and therefore might engage in unprotected sex, (3) are at increased risk of sexual violence, in particular women and girls with disabilities and (4) have less access to treatment services [1, 5-7]. This increased risk is reflected in the few HIV-Prevalence Studies that include people with disabilities, which suggest that infection levels are equal to or higher than the national average [8-10], and that girls and women with disabilities are particularly at risk [7].

Second, it has been argued that people living with HIV (PLHIV) experience disability as a result of HIV-related stigma and discrimination that they experience[7].

Third, there is increasing evidence that PLHIV may experience HIV-related disability either as a result of HIV, AIDS or, as a side-effect of HIV-related treatment [11-14]. HIV-related disability can result from a diverse range of HIV-associated conditions affecting the body such as neurological conditions resulting in strokes, cardiovascular system changes that result in heart attacks, musculoskeletal problems related to osteoarthritis and accelerated osteoporosis, changes in sexual function, changes in the digestive system, HIV dementia, mental health problems, as well as problems with vision and hearing.

Within the convention *universal design* is understood as designing “products, environments, programmes and services so that they are usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” [1]. Building ramps within a school or hospital is such a universal design as it means that people with physical disabilities should have access to such buildings without assistance.

*Reasonable accommodation* means necessary and appropriate modification and adjustments, not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others...” [1]. This means for instance providing a wheelchair or a sign interpreter for people with disabilities would be a form of reasonable accommodation.

However, despite the growing evidence on the interrelationship between disability and HIV, PWD

have largely been excluded from the national response to HIV and AIDS and existing related frameworks. National Strategic Plans (NSP) often fail to identify the vulnerability of people with disabilities to HIV as well as the reverse relationship of PLHIV to disability [15-17]. Inclusion in this framework allows a human rights-based approach, based on disability rights set out in the CRPD, and its principles of universal design and reasonable accommodation. Additionally, the UNAIDS International Guidelines on HIV/AIDS and Human Rights (UNAIDS, 2006) is a guiding tool for the rights of persons living with HIV/AIDS.

The UN Convention on the Rights of Persons with Disabilities (CRPD) states that State Parties need to “enable persons with disabilities to live independently and participate fully in all aspects of life”. Therefore, “State Parties shall take appropriate measures to ensure persons with disabilities on an equal basis with others, have access to the physical environment, to transportation, to information and communications, including information and communication technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas”. To achieve this goal the convention has two guiding principles: (1) universal design and (2) reasonable accommodation. The UNAIDS (2006) International Guidelines on HIV/AIDS and Human Rights recommend that states adopt a rights-based approach to HIV and AIDS. It provides concrete guidelines to



states on legislative and policy measures to reduce HIV-related stigma and discrimination and to create an enabling legal and regulatory framework that reduces vulnerability to HIV and mitigates the impact of HIV on those affected, in particular amongst vulnerable populations. The rights articulated in these two international documents form the basis for this framework.

## **1. Purpose**

This framework is a tool to guide the development and review of NSPs across the globe in terms of their disability-inclusiveness, and to realize the commitments of the CRPD and the International Guidelines on HIV/AIDS and Human Rights in advancing important policy frameworks in the context of HIV and AIDS. The framework, its language and its content, has been developed in alignment with regional and international commitments relating to HIV and to disability. It reflects the structure and format of current NSPs and includes step by step guidelines on integrating disability into plans and programmes at different levels. As such, it may provide guidance, accountability or can be used as a template.

It may guide the development or review of NSPs by governmental entities such as the National AIDS Council (NAC), Ministries of Health, Welfare and Social Services, Justice, Constitutional Development and other related ministries, as well as disability advisors. It can be used in conjunction with the framework for women, girls and gender equality [18]. The framework can also support civil society participation in and mobilisation around NSP development and review by important organisations such as Disabled Peoples Organisations (DPOs). Furthermore, Civil Society Organisations (CSOs) can use the tools and links to hold governments accountable in relation to disability inclusiveness.

## **2. Background and Guiding Principles of an NSP (1/3 page)**

An NSP's background analysis needs to include HIV and disability issues such as:

- Information on incidence and prevalence of HIV amongst people with disabilities (PWD)

- PWD, in particular girls and women with disabilities, as a vulnerable population
- An accurate description of the impact of HIV and AIDS on PWD
- An understanding of the specific vulnerabilities of people with disabilities
- An understanding of the disabling impact of HIV upon those infected
- A quantitative analysis of HIV-related disability found in this particular context

The CRPD (2008) as well as the UNAIDS International Guidelines on HIV/AIDS and Human Rights (2006) emphasise a rights-based approach towards disability or HIV/AIDS. The following key principles should form part of a disability inclusive national framework to address HIV and AIDS:

- Inclusion of PWD in the national response to HIV and AIDS
- Protection of the rights of PWD and the prohibition of unfair discrimination based on HIV and disability
- Provision of accessible HIV-related prevention, treatment, care and support services accommodating the needs of PWD and using the principles of equality, non-discrimination, universal design and reasonable accommodation
- Provision of information and training on the rights of PLHIV and PWD as well as provision of accessible legal services
- Inclusion of disability in mainstream research, monitoring and surveillance of the epidemic

### **3. National Framework to respond to HIV and AIDS**

Each NSP tends to include detailed provisions for the national institutional framework to govern the response to HIV and AIDS. These structures and processes need to involve people with disabilities (PWD). Representatives of people with disabilities should be:

- Included on national multi-sectoral structures set up to guide and oversee the national response to HIV and AIDS (e.g. as a key sector in the National AIDS Councils)
- Involved in the design, implementation, monitoring and evaluation of the national response through various mechanisms

Traditionally, people with disabilities are marginalised. A large number of these persons are among the world's poorest. The national framework needs to provide formal mechanisms to facilitate ongoing dialogue and input from the disability sector. Disabled Peoples Organisations (DPOs) may need capacity building to participate effectively. Support for the development of this infrastructure should be included in the national framework.

## **4. Priority Areas and Strategies of an NSP**

### **4.1 Human Rights Approach – Equality and Non-Discrimination**

NSPs often include protection of the rights of people living with HIV (PLHIV), those affected by HIV and AIDS and vulnerable populations at higher risk of HIV exposure. Rights-protection aims to reduce stigma and discrimination on the basis of HIV and AIDS, ensure that PLHIV have full access to their rights and also to reduce vulnerability to HIV infection amongst vulnerable populations. Rights-based protection in an NSP should include protection on the basis of HIV and disability. In addition, NSPs often mention the special protection of vulnerable populations, which should include people with disabilities (PWD). The NSP needs to provide for various measures to protect and promote equality and non-discrimination on the basis of disability and HIV. Measures may include, amongst others:

- Reviewing laws and policies to protect the rights of people on the basis of disability and HIV
- Developing education programmes that increase understanding and reduce stigma and discrimination against PLHIV, PWD and other vulnerable populations
- Strengthening appropriate and accessible access to justice for PLHIV and PWD (e.g. through the provision of legal support services)
- Strengthening mechanisms to monitor and enforce the rights of PLHIV and PWD, and
- Training health care and other service providers on the rights of PLHIV and PWD

### **4.2 Health Related Services**

All NSPs identify specific priority areas in relation to prevention, treatment, care and support in order to reduce the spread of HIV as well as manage the impact of HIV and AIDS on those infected and affected

by the disease. All prevention and health services should recognise the barriers to access to services and reasonably accommodate the needs of people with disabilities. Prevention, treatment, care and support programmes therefore need to be provided in an accessible and appropriate format through:

- Developing universal designs of services such as the inclusion of ramps in buildings
- Developing specialised formats such as material and packaging in Braille, sign language interpretation and simplified information to compensate for intellectual challenges
- Including the provision of rehabilitative and mental health services for people living with HIV who experience HIV-related disability
- Including measures to address HIV and disability-related stigma and discrimination within health services
- Developing a disability sector plan that provides more detailed and practical guidance on how to implement disability inclusive services
- Providing budget allocation for disability services

#### **4.3 Legal Support Services**

NSPs need to include measures to create an enabling framework to protect and promote human rights of people infected and affected by HIV and AIDS and people with disabilities. For example, NSPs may:

- Provide for the inclusion of information and training in regards to the rights of person with disabilities as well as interventions to reduce stigma and discrimination
- Address the provision of access to justice for people with disabilities and those affected by HIV
- Include disability specific support to access justice in the context of HIV and AIDS

#### **4.4 Research, Monitoring and Surveillance**

Most NSPs identify research, monitoring and surveillance as a priority area. The participation of people with disabilities in the design, analysis and delivery of monitoring and research is critical. This section of the NSP needs to include disability and ensure the following are included:

- Disability indicators in national surveys, so it is easy to determine HIV-prevalence in people with disabilities as well as risk behaviour and gaps in service delivery

- Disability indicators in the treatment of people living with HIV (e.g. ICF)
- Indicators on the impact of programmes and policies on people with disabilities
- Participation of people with disabilities in the design, analysis and delivery of research
- Demonstration of the long term transformative processes in terms of disability and social norms
- Demonstration of the effectiveness of disability inclusive or specific programmes

## 5. Resource Mobilisation

Operationalizing the principles described above will only occur if resources are mobilised for a disability inclusive approach. Ideally, this requires budgetary allocations throughout the NSP or its operational plan. Examples of the types of programme activities that should be included in the budget are:

- Adapting prevention messages to meet the special needs of such impairments as blindness, deafness and intellectual disability
- Accommodating the special needs of PWD within National AIDS Council structures (e.g. sign interpreter); and
- Undertaking a baseline study to establish the number of PWD
- Capacity building of NGOs, DPOs and health care providers
- Providing accessible services e.g. sign interpreters
- Providing legal support to PWD
- Providing rehabilitation and mental health services for PLHIV
- Ensuring that language is not a barrier in our outreach to the varied populations served

The activities and related costs might be challenging for countries that have already adopted their new NSP or are in resource constrained settings.. Nevertheless countries could work incrementally towards resource mobilisation for a disability inclusive approach through developing:

- An additional disability sector plan or approach that also identifies opportunities for resource mobilisation;
- Partnerships with the disability community through NGOs working with PWD and DPOs (Disabled Peoples

Organisations). This should focus on enabling organisations to submit successful proposals to agencies such as the Global Fund or other international donors. Many of these agencies have developed disability policies in the past years and are therefore obliged to include disability in their development work. Article 32 of the CRPD also requires state parties ( also donor countries) to develop “inclusive and accessible” development programs and to provide “technical and economic assistance” as well as “capacity building” in regards to disability; and

- Links with existing state programmes on disability which may be able to reallocate resources to HIV issues.

Finally, countries could also in the interim undertake activities which have limited resource implications. For example, NGO partnerships could focus on the inclusion of these organisations in already existing structures and programmes as well as encourage capacity building for existing structures on the rights of PWD.

## **6. Step by Step guidelines (or a roadmap to inclusion)**

This section provides a road map for the inclusion of disability and attempts to map out goals for countries on different levels of the pathway.

### *6.1 Initiating Inclusion of Disability (initiation step)*

- Signing and ratifying the Convention on the Rights of Persons with Disabilities (CRPD)
- Including disability as a sector within the National AIDS Council structures ( minimal costs for accommodating special needs)
- Commissioning baseline research to provide a situation analysis and ideas for feasible next steps (research one-time costs)
- Mobilising partnerships and resources to develop a disability sector plan/strategy
- Networking and sharing good practices across a region (minimal start up costs)

### *6.2. Domesticating CRPD into law and national frameworks (developing legal and other norms on disability step)*

- Domesticating the CRPD into legal frameworks, laws and policies

- Capacity building around disability and HIV
- Developing a disability sector plan and submitting it to funders
- Developing integrated pilot projects on disability and HIV

### 6.3 *Developing feasible approaches* (towards integration step)

- Integrating disability into the National Strategic Plan (situation analysis and priority areas)
- Allocating resources to disability in key strategic areas (in budget and/or operational plan)
- Integrating disability indicators into national surveys and prevalence studies

### 6.4 *Monitoring and Implementation of disability inclusive programmes* (optimal inclusion step)

- Developing monitoring and evaluation tools
- Annual reporting on statistics in relation to disability and HIV
- Mainstreaming disability into all relevant programmes such as prevention, treatment, care, support and surveillance

## 7 **Resource Websites**

UN Enable <http://www.un.org/disabilities/default.asp?id=1560>

HEARD Resource Centre <http://www.heard.org.za/african-leadership/disability>

Source resources <http://www.asksource.info>

UNAIDS: [http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf)

## 8 **Contributing organisations**

This framework has been developed by the Global Contact Group on AIDS and Disability (GCGAD) NSP task group in cooperation with UNAIDS. It has been inspired by the Framework for Women, Girls, and Gender Equality [18] and the Health Economics and HIV/AIDS Research Division (HEARD) NSP review [16, 19, 20].

We would like to thank all who contributed to the development of the disability and HIV NSP framework in particular the core drafting team Catherine Grant (HEARD), Dr. Jill Hanass-Hancock (HEARD), Ann Strode (School of Law, The University of KwaZulu-Natal) as well as the NSP task group members Darryl Barret (Barrett Advocacy and Training), Steven B. Estey (AIDS-Free World), Prof. Nora Ellen Groce (University College London), Martine Mangion, Canadian Working Group on HIV and Rehabilitation (CWGHR), Muriel Mac-Seing (Handicap-International), Phillimon Simwaba, Disability, HIV and AIDS Trust (DHAT) and Dr. Emelia Timpo, Joint United Nations Programme on HIV/AIDS (UNAIDS).

## 9 Appendices

- HEARD NSP analysis tool to download at <http://www.heard.org.za/downloads/inclusion-of-disability-in-nsp-in-southern-and-eastern-africa-analysis-tool.pdf>
- HEARD NSP analysis guide to download at <http://www.heard.org.za/downloads/inclusion-of-disability-in-nsp-in-southern-and-eastern-africa-analysis-guide.pdf>

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## Appendix 11 Health Services Checklist

*The following checklist provides you with some guidance in order to make your health services more accessible and disability friendly. Please answer yes/no/not sure if your facility is designed in an accessible and disability friendly manner. Please tick the last column “things I can change/influence” if you feel that you can influence or change these aspects.*

Is your health care facility designed universal?				
Do you have the following:	Yes	No	Not sure	Things I can change/influence
Ramps to access your buildings and outside areas				
Crucial services on the ground floors				
Doors that fit a wheelchair and open easily				
Wheelchair accessible toilet				
Railings along the corridors or outside areas				
Directions on key areas in Braille (e.g. lifts, signposts)				

Does your health facility accommodate special needs?

Do you have the following:	Yes	No	Not sure	Things I can change/influence
Disability desk at the entrance area				
Preferable treatment so people with disabilities don't have to stand in long cues				
Sign language interpretation and information in pictures for the deaf				
Information in Braille or in audio format				
Beds that accommodate physical disabilities through height adjustments particularly in the maternity ward				
Simplified information for people with intellectual disabilities related to counseling				
Simplified information for people with disabilities related to treatment				
Simplified information for people with disabilities related to abuse				
Medication boxes with symbols, pictures or Braille to accommodate special needs				
Staff who have a disability				

Is your staff trained to screen for disability and refer to the right services?				
Have your staff been exposed to the following:	Yes	No	Not sure	Things I can change/influence
Anti-stigma training focusing on disability and HIV				
Training on sign language interpretation and Braille				
Training course focusing on the interrelationship of disability and HIV (sensitization)				
Training on health rights of people with disabilities				
Training to screen for disability including mental health in general services such as ART				
Referral systems to rehabilitation including Community Based Rehabilitation				
Staff who have a disability				

Is your health service linked to poverty alleviation for people with disabilities?				
Are your health services linked to the following:	Yes	No	Not sure	Things I can change/influence
Back to work programs for people who acquired a disability				
Food security programs that include people with disabilities				
Sheltered employment				
Referral system to social work, disability grants or business loans				

Is your HIV program linked to disability services and rehabilitation?				
Do you have the following:	Yes	No	Not sure	Things I can change/influence
Referral system from disability services to reproductive health services and VCT				
Screening tools to identify disability including mental health problems in your ART program				
Referral system from ART and VCT program to rehabilitation and mental health services				
Rehabilitation department is trained and equipped to address HIV-related disability				

Is your health service linked to community services?				
Are your health services linked to the following:	Yes	No	Not sure	Things I can change/influence
Home Based Care				
Community Based Rehabilitation				
Food security programs				
Livelihood programs that focus on people with disabilities				
Disabled Peoples Organisations				
NGOs that focus or include people with disabilities				

## Appendix 12a PRE WORKSHOP EVALUATION FORM

**INSTRUCTIONS:** Please complete this form accordingly to help the workshop facilitators gather necessary information that will ensure that the workshop adequately meets your training needs.

1. Participant name: \_\_\_\_\_

2. Gender \_\_\_\_\_

3. Date of birth: \_\_\_\_\_

4. Name of employer: \_\_\_\_\_

5. Current job position: \_\_\_\_\_

6. Have you attended a similar workshop before? Yes  No

7. If yes, when and where did you attend the course?

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8. State your key responsibilities in your current job

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9. What are your key expectations of this workshop?

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10. How do you intend to use the knowledge and skills from this workshop in your work?

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11. How do you intend to use the knowledge and skills from this workshop as an individual?

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## Appendix 12b END OF WORKSHOP EVALUATION FORM

**INSTRUCTIONS:** Please complete this form accordingly to help the workshop facilitators gather necessary information that will ensure that the workshop adequately meets your training needs.

Participant name: \_\_\_\_\_

Gender \_\_\_\_\_

Date of birth: \_\_\_\_\_

Name of employer: \_\_\_\_\_

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Please rate the following statements on a scale from 1 to 5 with 1 = strongly agree and 5 = strongly disagree

1. The objectives of the workshop met my training needs

1	2	3	4	5
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2. The workshop content was relevant to my work

1	2	3	4	5
---	---	---	---	---

3. The workshop improved my understanding of the subject matter

1	2	3	4	5
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4. The workshop provided new knowledge and practical skills ideas for improving my professional work

1	2	3	4	5
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5. What are the key ideas that you have taken away from the workshop to implement or use

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6. How do you intend to use these ideas at work

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